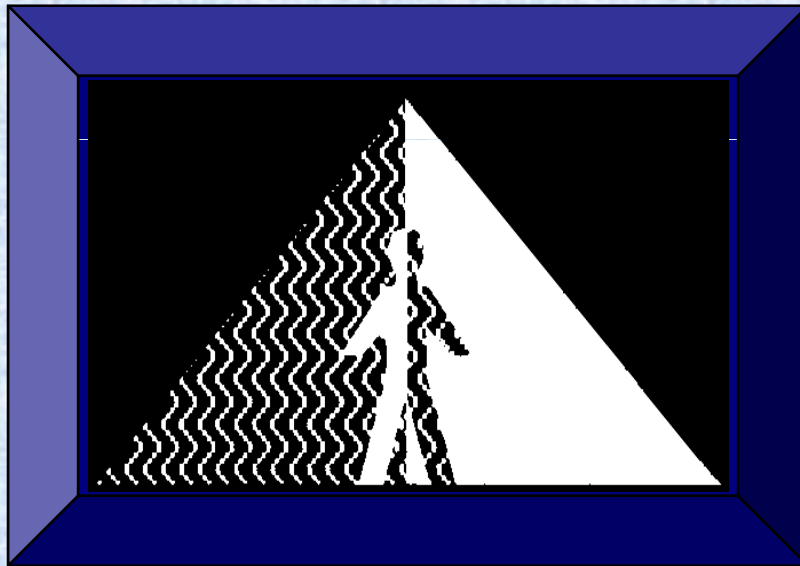
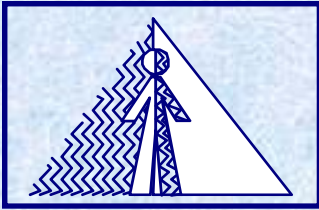


Older Under-served Populations Across the Cancer Continuum

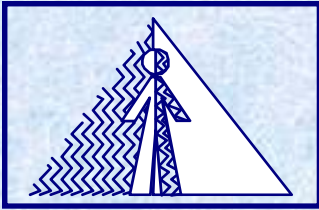


Merle H. Mishel, PhD
Barbara Germino, PhD

**The University of North Carolina at Chapel Hill
School of Nursing**

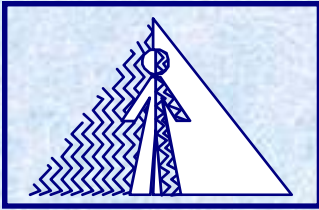


Enhancing Recruitment, Retention and Positive Outcomes of African- American Cancer Patients: Experience from Nursing- Intervention Studies



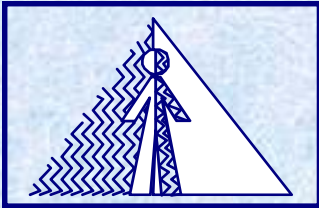
Barriers to Minority Participation In Research

- **Cancer fatalism**
- **Fear and mistrust**
- **Costs in money and time**
- **Difficult access to research site**
- **Jargon-laden information**



Barriers to Minority Participation In Research

- **Lack of community familiarity with research**
- **Ethnic, cultural, racial differences between researchers and potential subjects**



Recruitment and Retention of African-American Cancer Patients

Psycho-educational intervention:

Study # 1 with older Caucasian American and African American Women during TX for Breast Cancer.

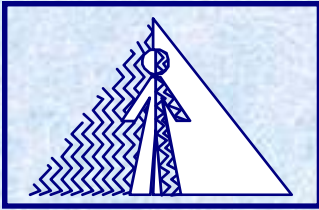
Study # 2 with older Caucasian American and African-American Men during TX for prostate cancer.

Study # 3 with older Caucasian American and African-American women who are long-term breast cancer survivors.



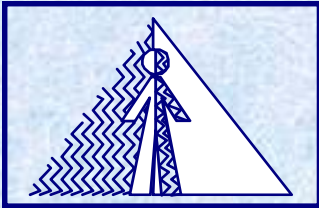
Expanding team's understanding about African-American's attitudes towards research

- Inclusion of African-American co-investigator
- Meetings and consultation with major AA minister who is a prostate cancer survivor
- Focus groups with AA breast cancer survivors from target communities
- Identified collaborative individuals in Eastern part of the state.



Planning recruitment strategies that engage the African-American community

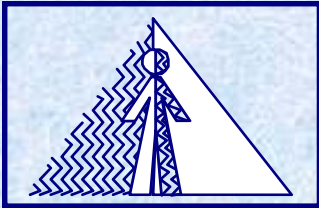
- Targeted regional hospitals with minority physicians as recruitment sites to reduce social distance
- Identified gatekeepers and community allies through contacts mentioned earlier
- Bi-weekly contact with key persons
- Hired 2 AA men and one AA woman as recruiters in the community (additional NIH funding)



Overcoming Distrust

Face to Face recruitment

- Participant choice for place to discuss recruitment
- Recruitment video narrated by well known political or entertainment person. Portable video.
- Minority nurse presents phone recruitment script.
- Familiarity with study enhanced by: bus posters; posters with tear off sheets in beauty parlors, barber shops; community centers; clinics; doctor's office.
- Flyers distributed in church.
- Announcement on radio stations; on public TV.

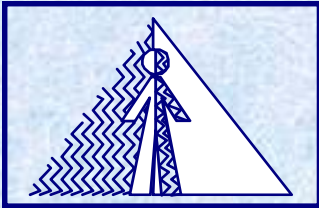


Overcoming Distrust

Targeting Cultural reluctance:

- Information booth at AA sororities and at AA Baptist state convention.
- Statewide teleconference hosted by well known AA men discussing the issue of prostate cancer in the community . Committing to educational efforts.

These activities provided information to widely dispersed communities about prostate cancer and our study.

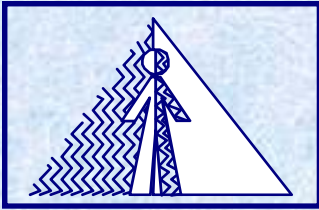


Outcome Measures and Intervention Delivery

Modification of outcome measures

Sensitivity to participant's limited income and resistance to come to study site:

- telephone delivered intervention
- home data collection
- consistent data collector
- intervener matched to subject by race and gender

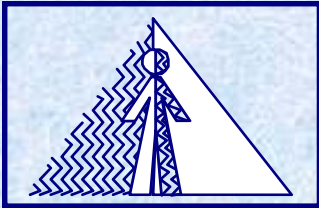


Outcome Measures and Intervention Delivery

Resource list designed for participant's Community.

Intervention not scripted in order to promote more normal flowing interaction.

Management strategies suggested by intervener selected to be within participant's educational and resource level.



Strategies for Addressing Retention

Two major approaches: provide participant as much choice as possible; keep interest alive via novelty.

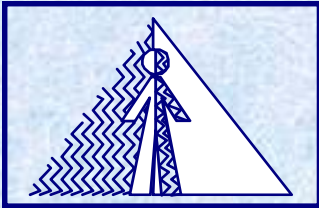
Data collection:

Choice by participant within a 2 work window.

Given 1-800 # to call to change date

Novelty:

Monthly incentive gifts.



Results

Attrition rate:

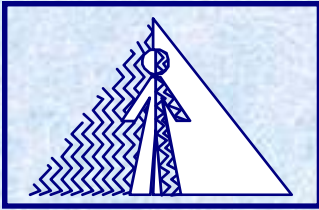
**AA women in breast cancer studies:
during TX 4%; survivorship 3.8%.**

AA men in prostate study: 4.4 % .



Managing Uncertainty in Cancer

Findings



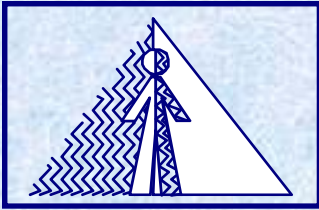
Major Problems of Men with Localized Prostate Cancer

Caucasian

- **Leaking urine**
- **Erection problems**
- **Communication with health care providers**
- **General side effects**
- **Fatigue**
- **Pain**

African-American

- **Leaking urine**
- **Communication with health care providers**
- **General side effects**
- **Erection problems**
- **Fatigue**
- **Pain**



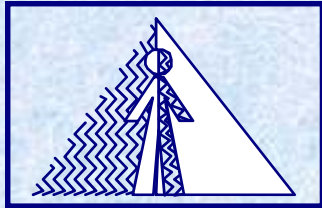
Major Problems of Women with Breast Cancer

Caucasian

- **Fatigue**
- **Medical Uncertainty**
- **Ability to Cope**
- **Implementing self-care behaviors**
- **Treatment Plan**
- **Finances**
- **Outcomes from treatment**
- **Co-morbidity**

African-American

- **Finances**
- **Fatigue**
- **Implementing self-care behaviors**
- **Nausea**
- **Expectations about treatment**
- **Pain**
- **Recurrence**
- **Skin Changes**



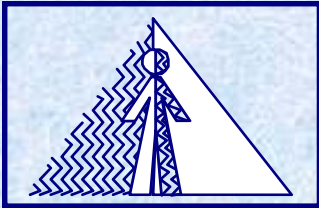
Interventions Used Most Frequently Among Men

Caucasian

- **Provide information on usual trajectory**
- **Promote assertive communication**
- **Provide information to manage incontinence**
- **Share experience with others**
- **Validate self-care**

African-American

- **Provide information on usual trajectory**
- **Promote assertive communication**
- **Provide information to manage incontinence**
- **Encourage a positive view of situation**



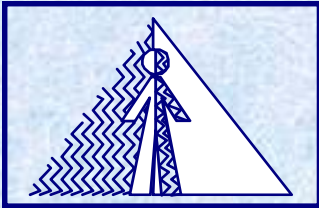
Interventions Used Most Frequently Among Older Women

Caucasian

- **Provide information and resources**
- **Validate self-care behaviors**
- **Communicate and validate views**
- **Clarify expectations**

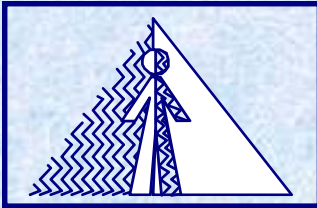
African-American

- **Provide information**
- **Validate self-care behaviors**
- **Encourage vigilance**
- **Put symptoms in treatment context**
- **Reinforce self-advocacy behaviors**



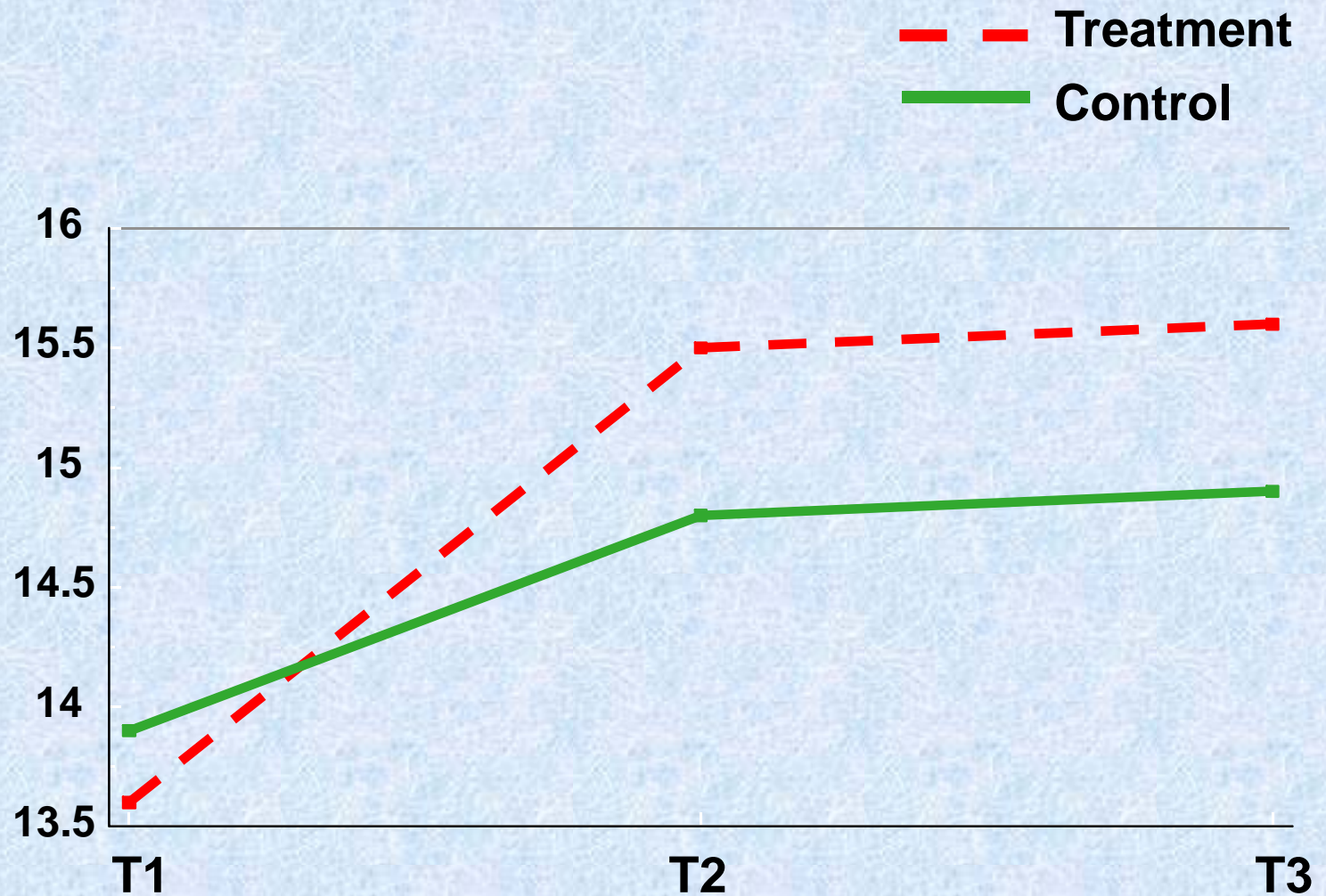
Managing Uncertainty in Breast Cancer

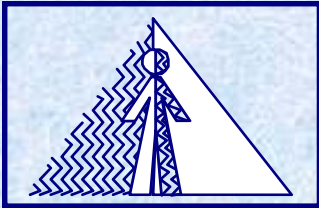
Results of Delivering Intervention



Cancer Knowledge

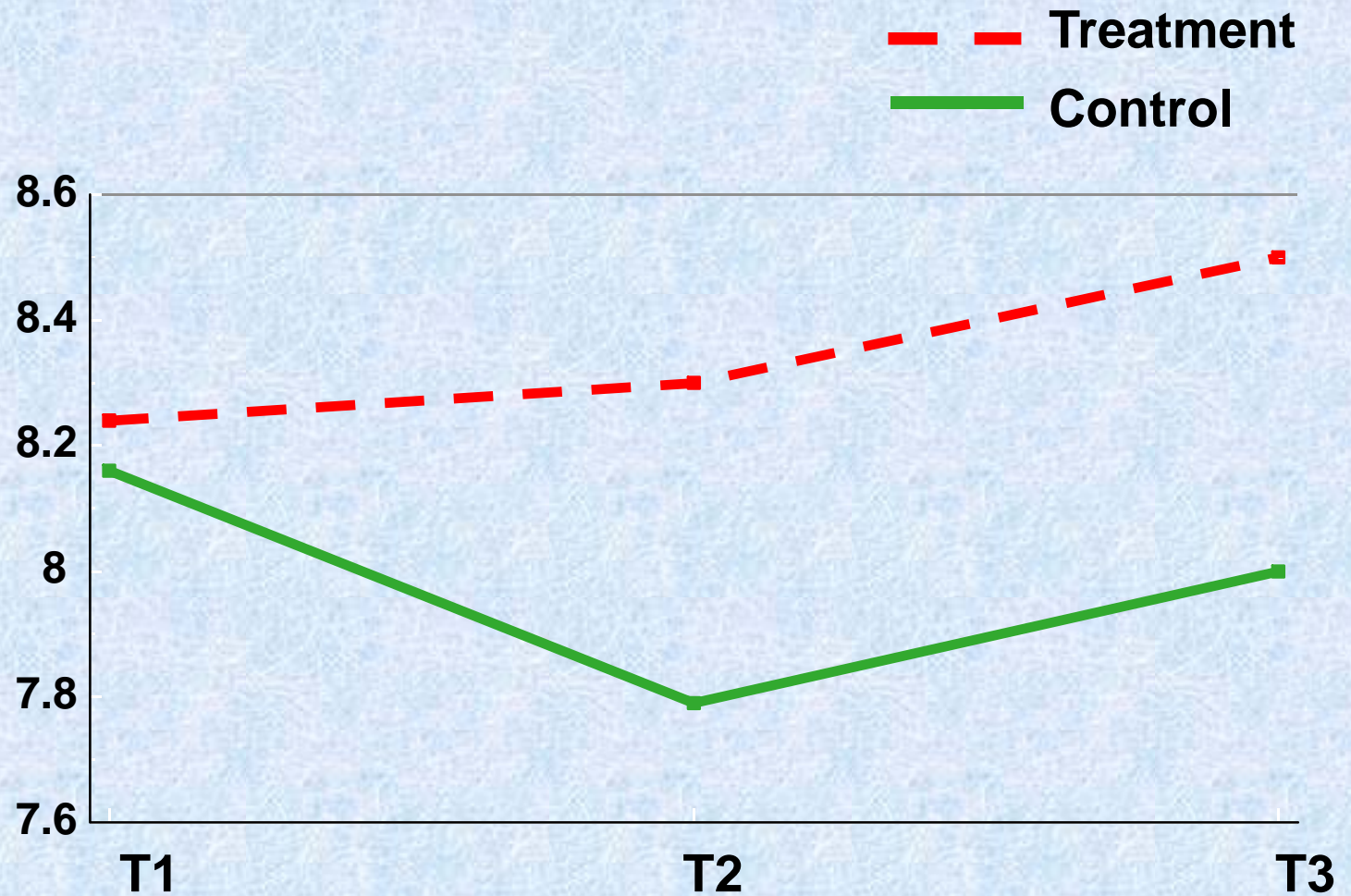
Caucasian and African American Women - Main Effect

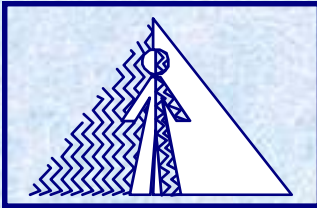




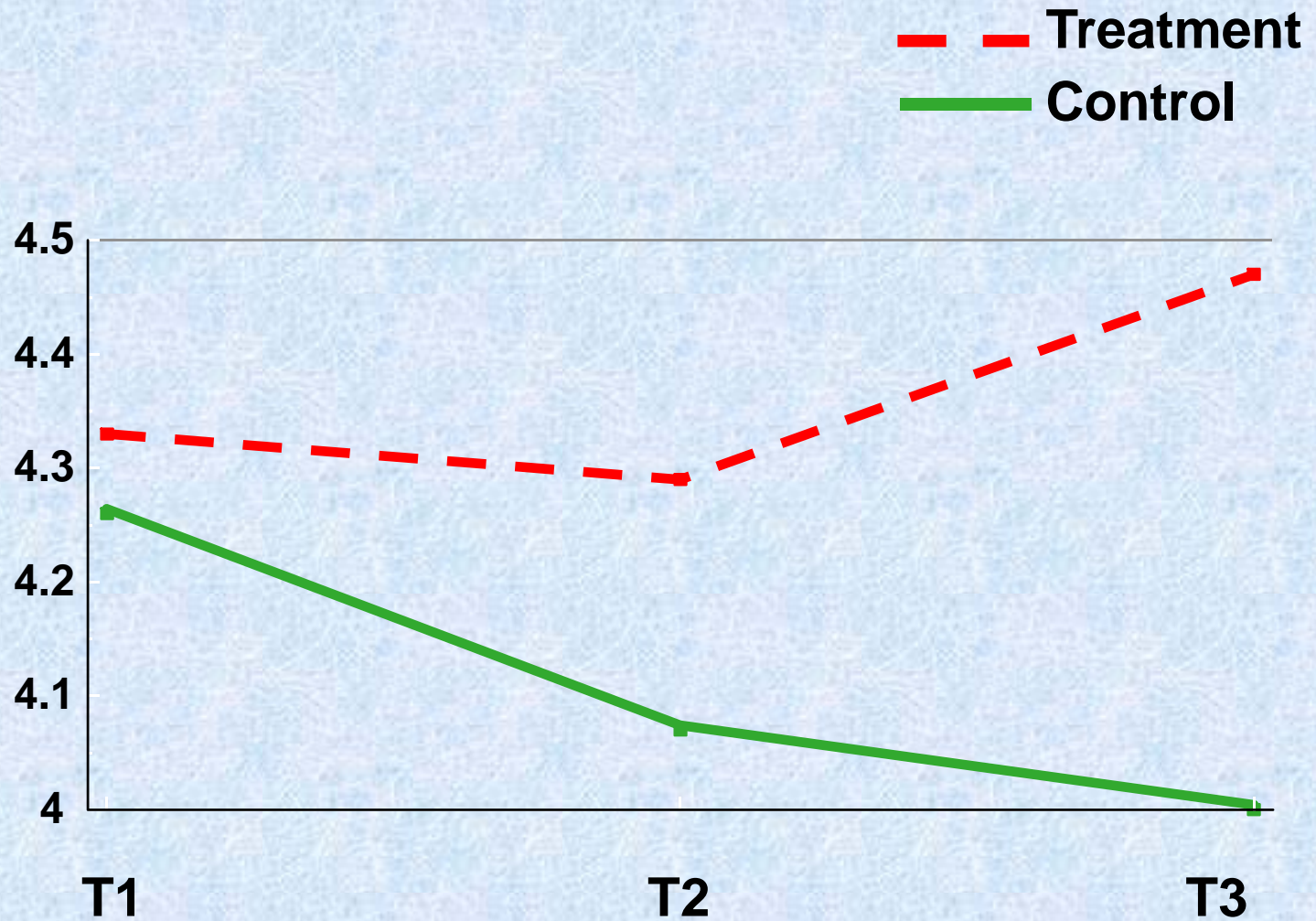
Problem Solving

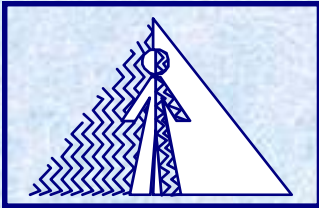
Caucasian and African American Women - Main Effect



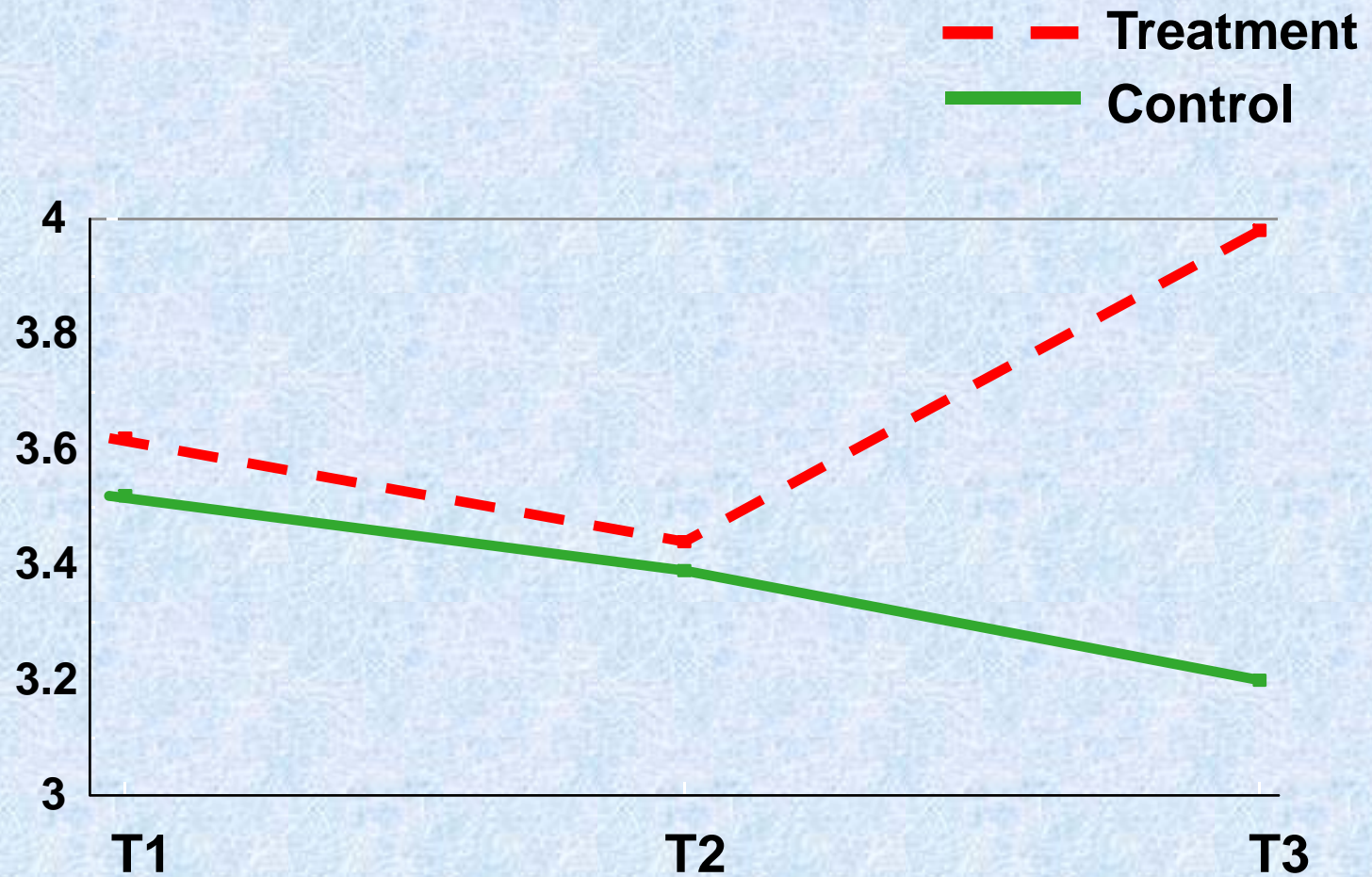


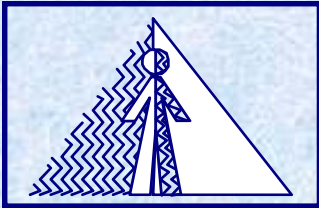
Obtaining Information from Physician Caucasian and African American Women - Main Effect





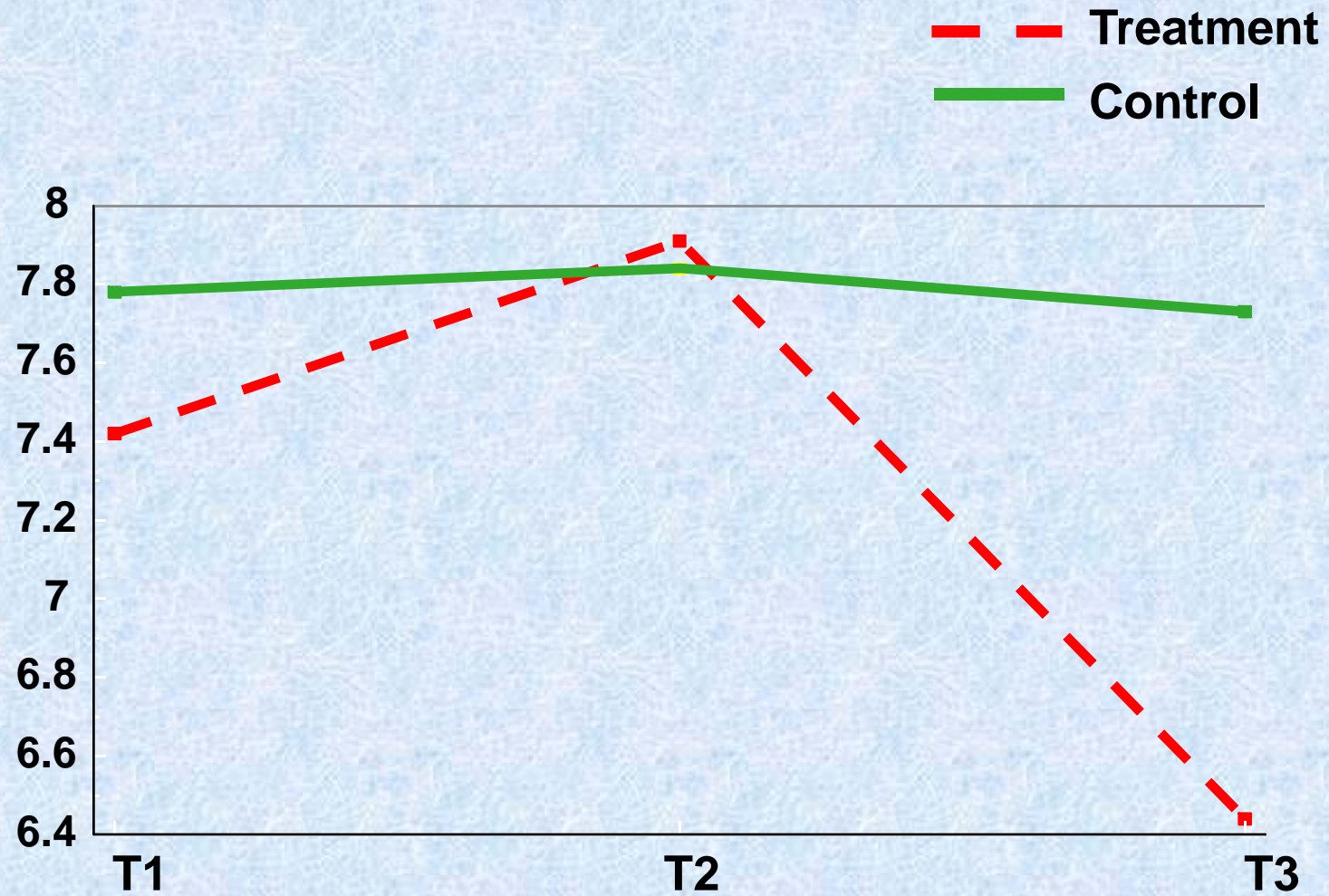
Obtaining Information from Nurse Caucasian and African American Women - Main Effect

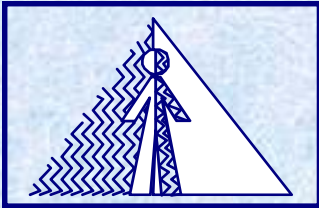




Number of Symptoms

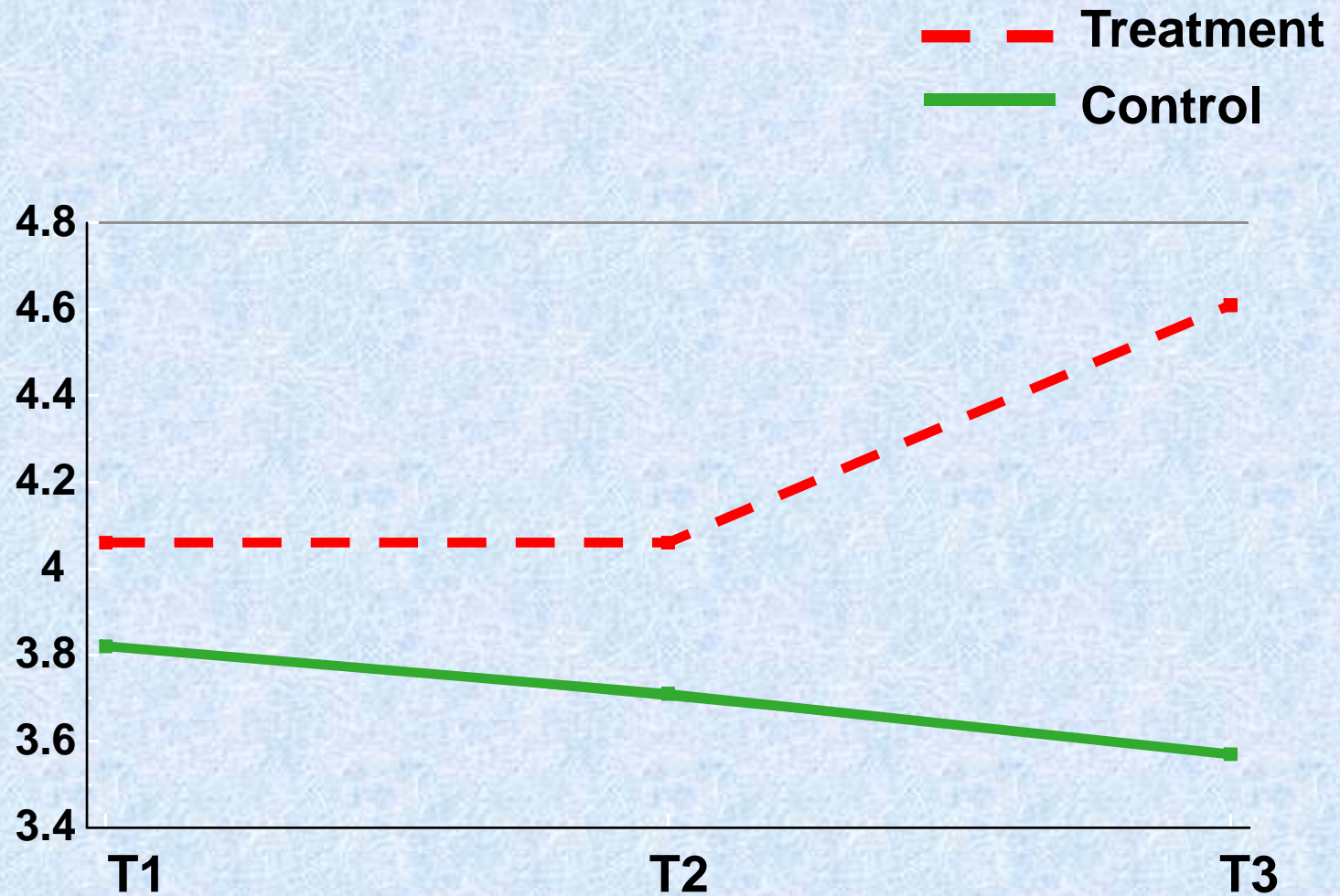
African American Women - Interaction Effect

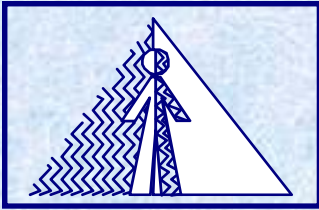




Fatigue (Higher scores = less fatigue)

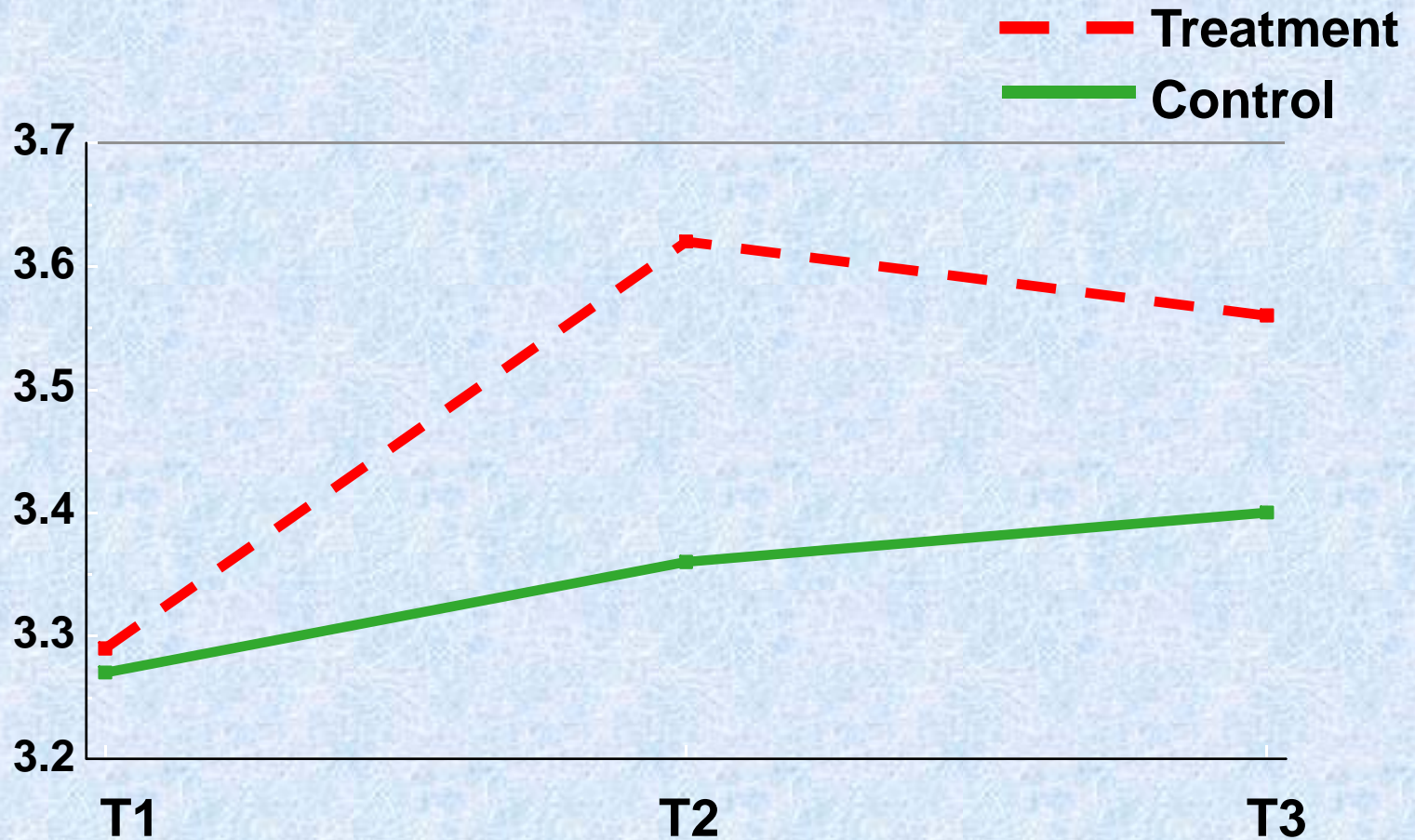
African American Women - Interaction Effect

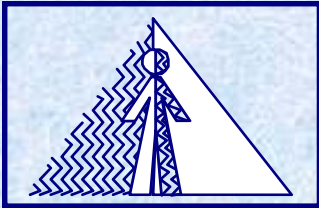




Work and Recreational Activities

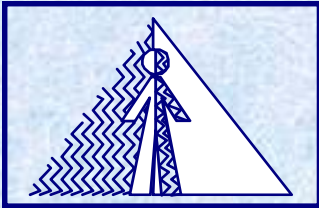
African American Women - Interaction Effect



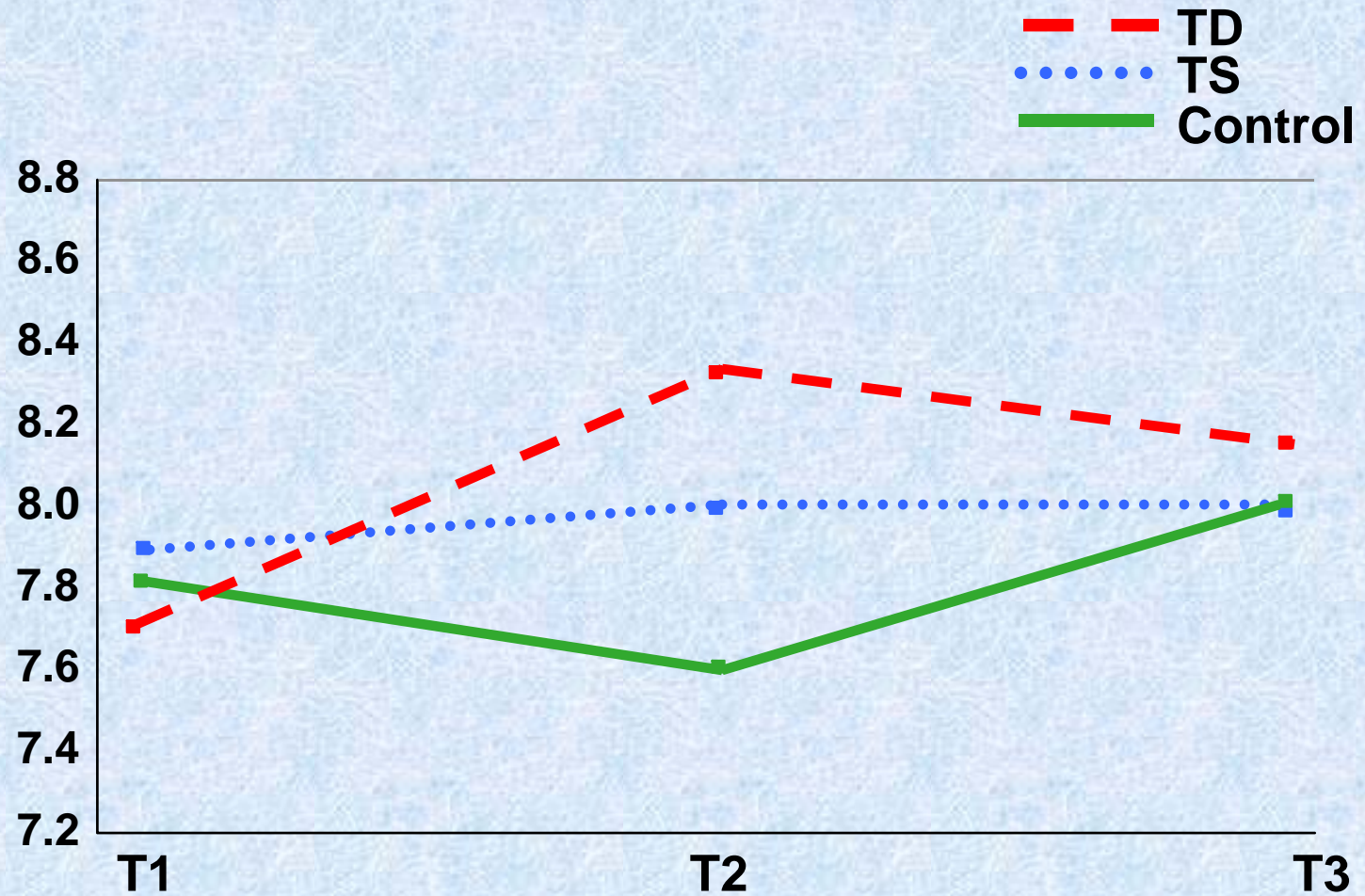


Managing Uncertainty in Men with Localized Prostate Cancer

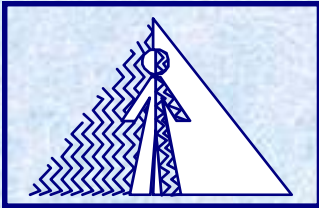
Results of Delivering Intervention



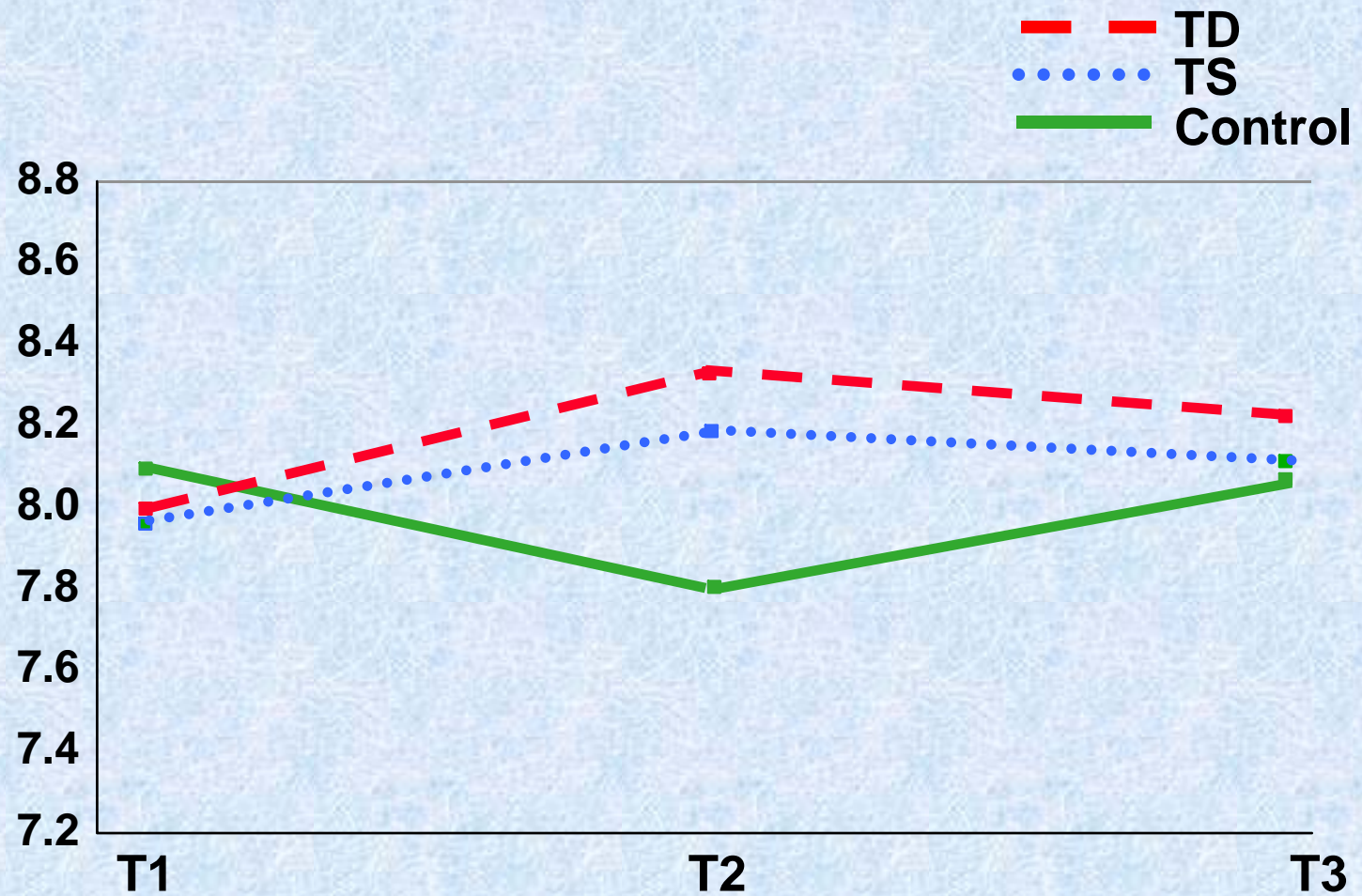
Cognitive Reframing



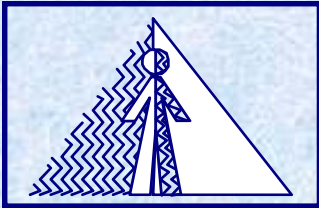
$F(4,456) = 3.81$ $P < .01$



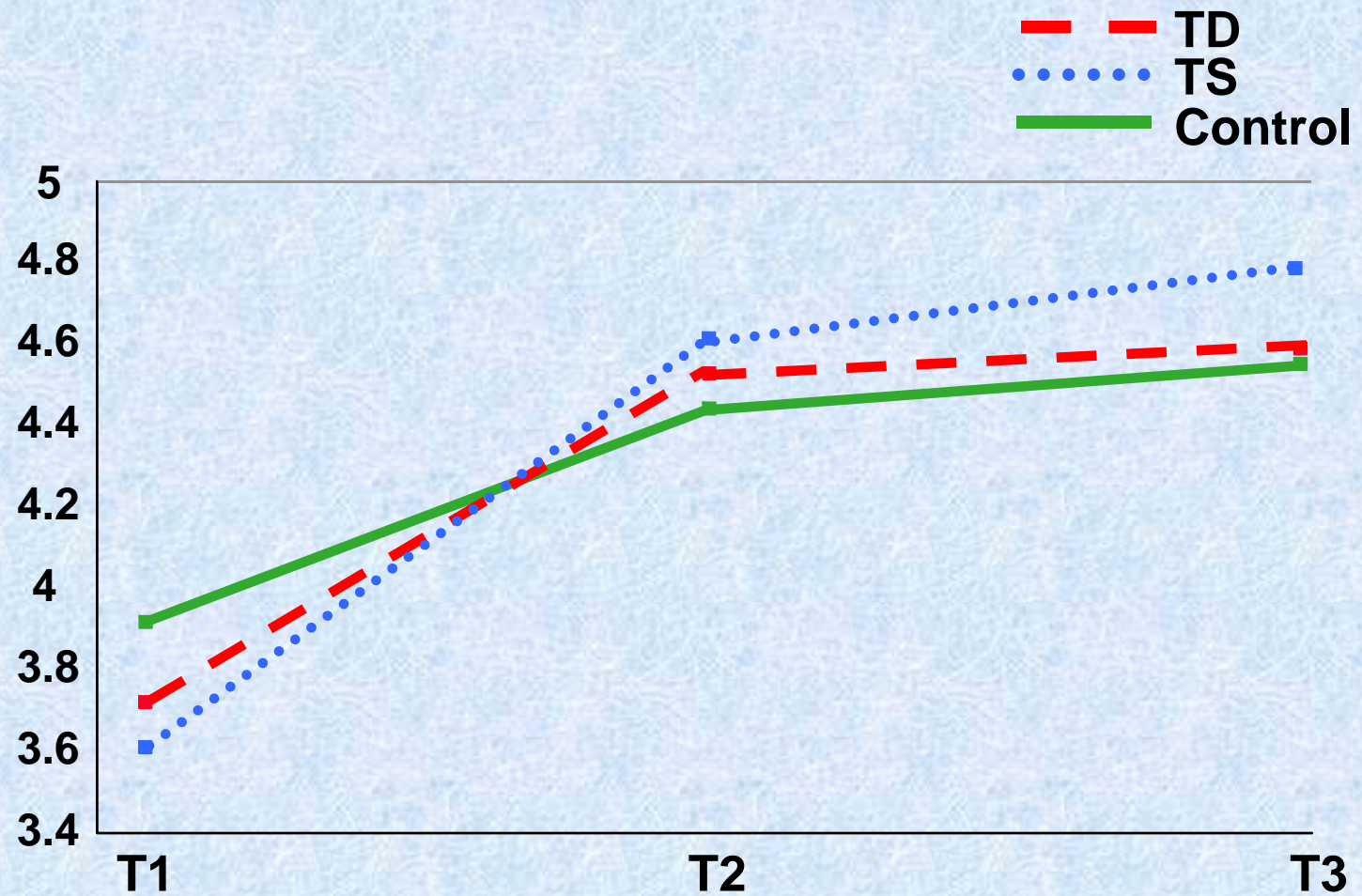
Problem Solving



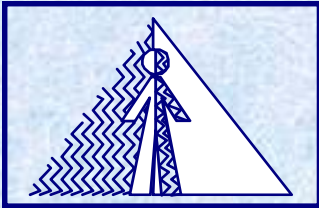
$F(4,456) = 2.40$ $P < .05$



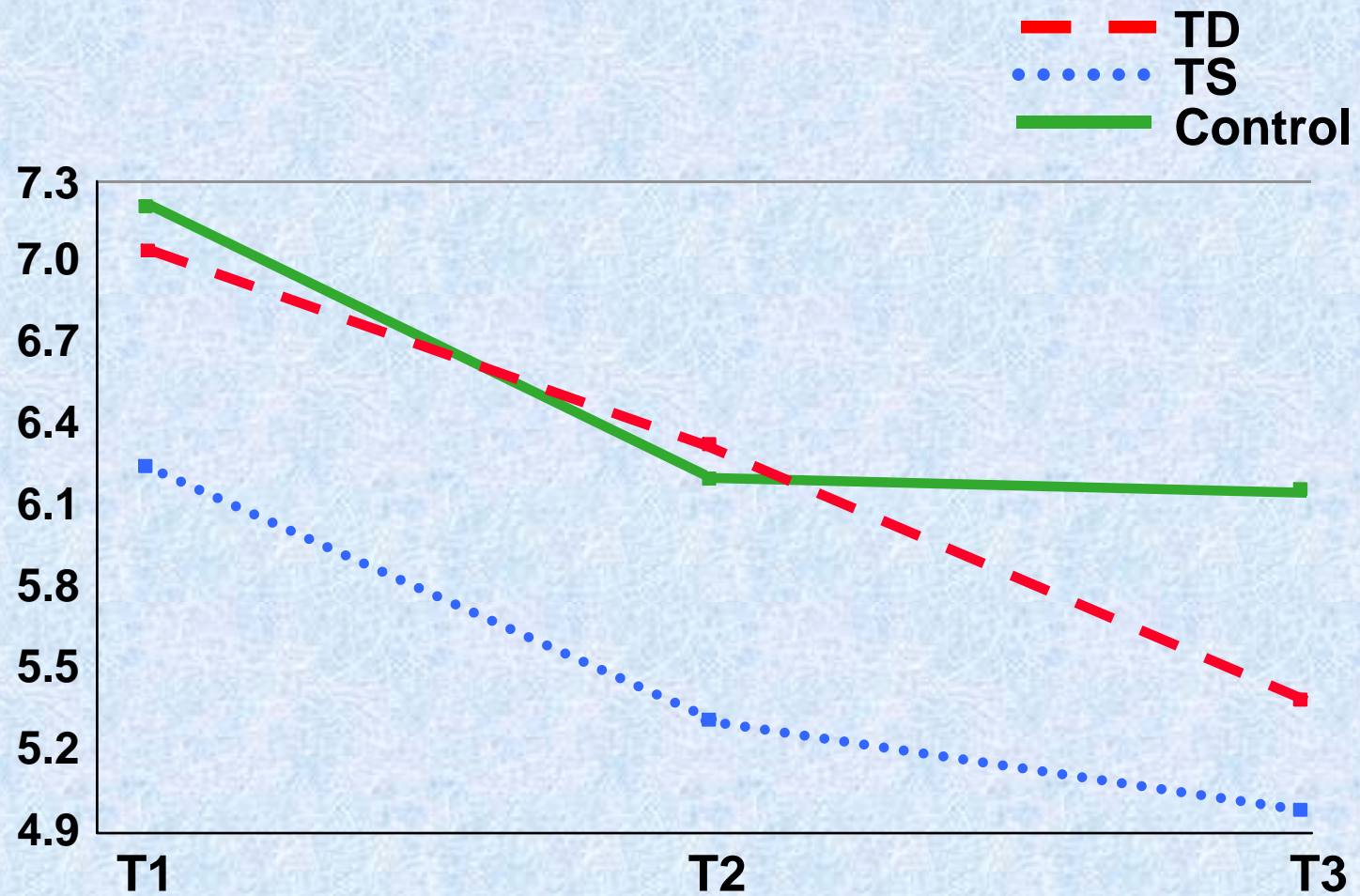
Control Over Urine Flow

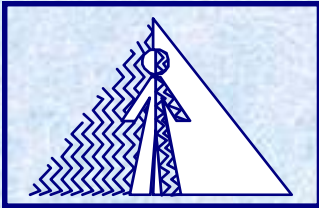


$F(2,228) = 3.07$ $P < .05$

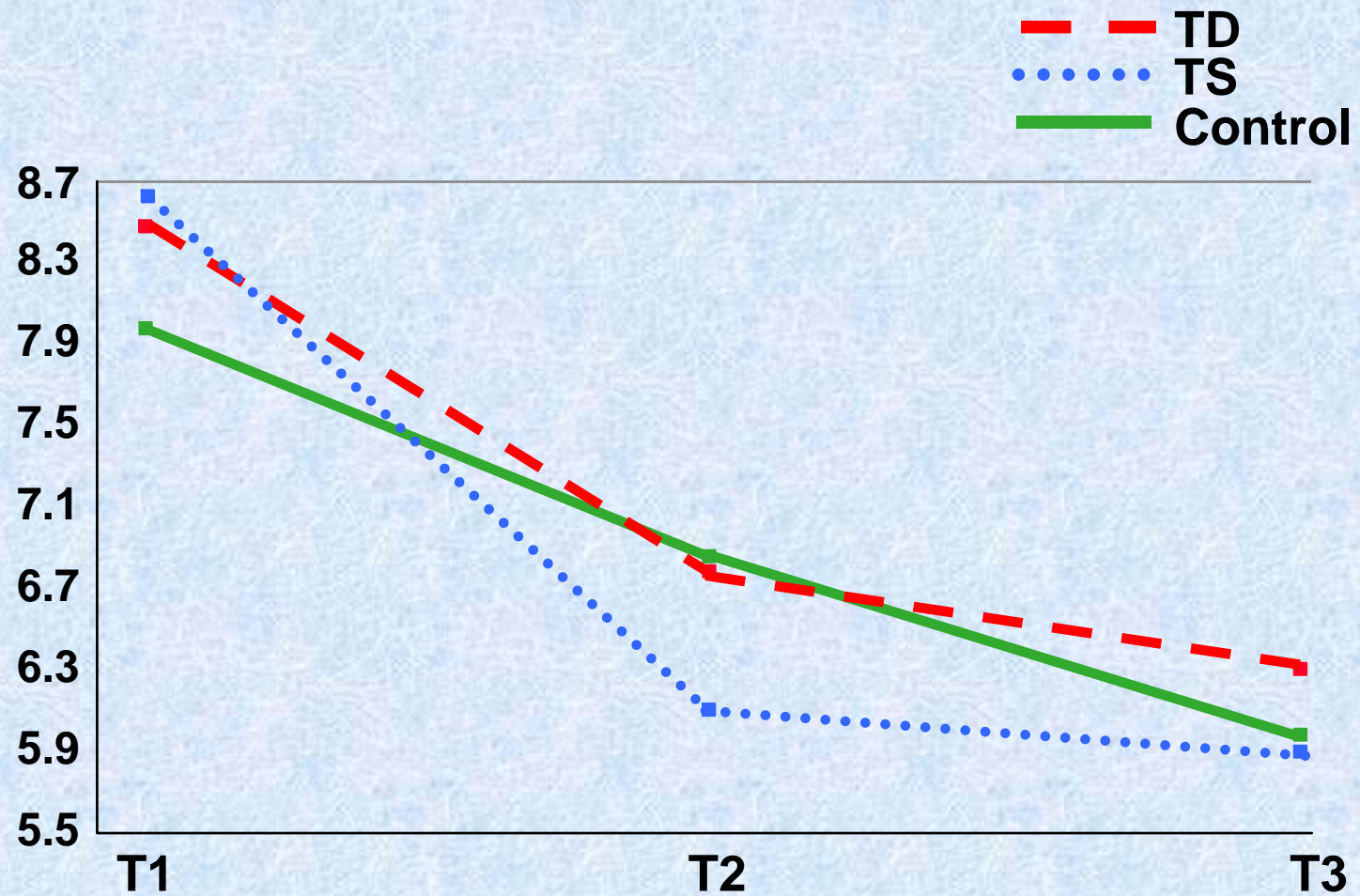


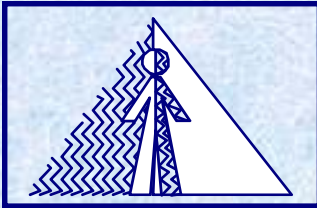
Number of Symptoms: African-American



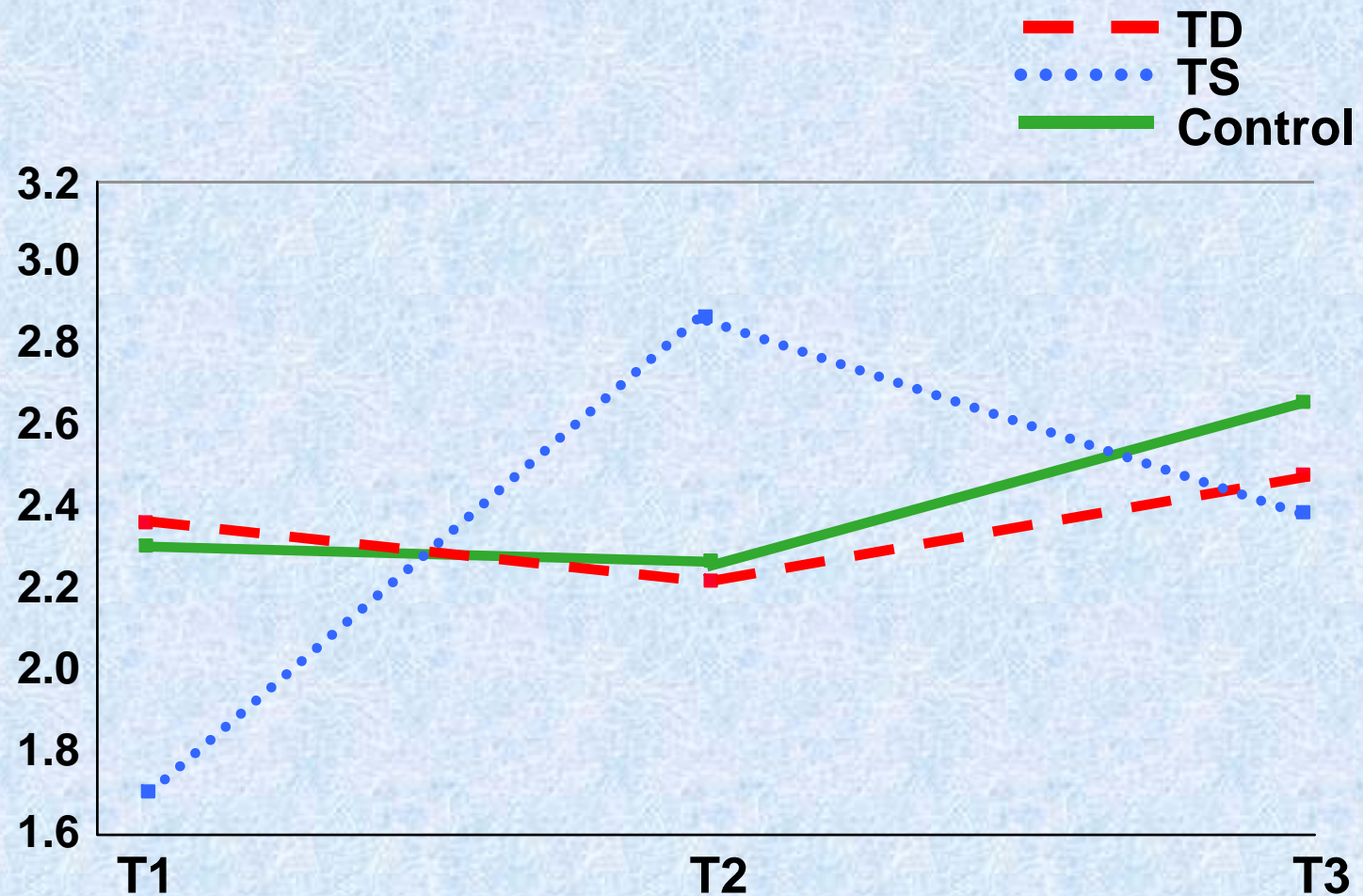


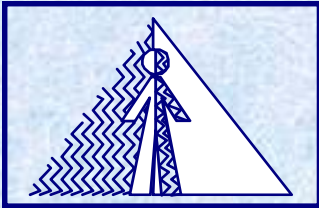
Number of Symptoms: Caucasian





Satisfaction with Sexual Functioning: African-American





Managing Uncertainty in Cancer- Long term Breast Cancer Survivors

Findings

Occurrence of Triggers by Ethnic Group

| <u>Trigger</u> | <u>Cauc</u> | <u>AA</u> |
|-------------------------|-------------|-----------|
| • New aches, symptom | 89% | 84% |
| • Someone else's cancer | 84% | 77% |
| • Environmental | 71% | 52%* |
| • Info from media | 64% | 60% |
| • Doctor appointment | 51% | 58% |
| • Bca controversy | 57% | 29%* |

Occurrence of Triggers by Ethnic Group

| <u>Trigger</u> | <u>Cauc</u> | <u>AA</u> |
|----------------------------|-------------|-----------|
| • Annual Mammogram | 46% | 49 % |
| • New TX side-effect | 42% | 44% |
| • Anniversary of diagnosis | 36% | 34% |
| • Dr. attending to symptom | 29% | 36% |

Occurrence of Symptoms by Ethnic Group

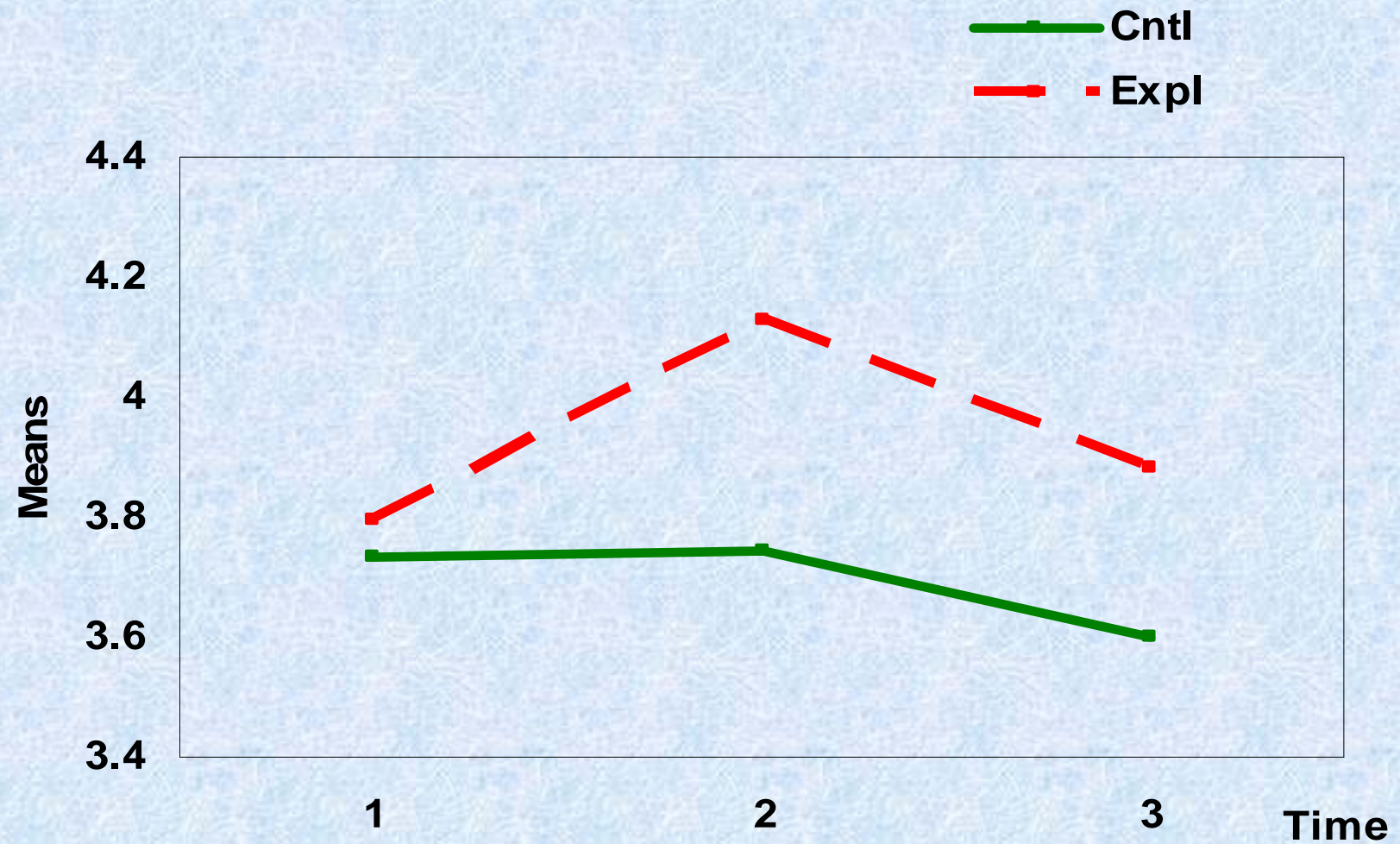
| <u>Symptom</u> | <u>Cauc</u> | <u>AA</u> |
|--------------------------|-------------|-----------|
| • Fatigue | 84% | 82% |
| • Joint Stiffness | 81% | 84% |
| • Pain | 75% | 78% |
| • Lymphedema | 56% | 55% |
| • Skin Changes | 51% | 47% |
| • Hormone/Sexual Changes | 43% | 40% |



Managing Uncertainty in older Long-Term Breast Cancer Survivors

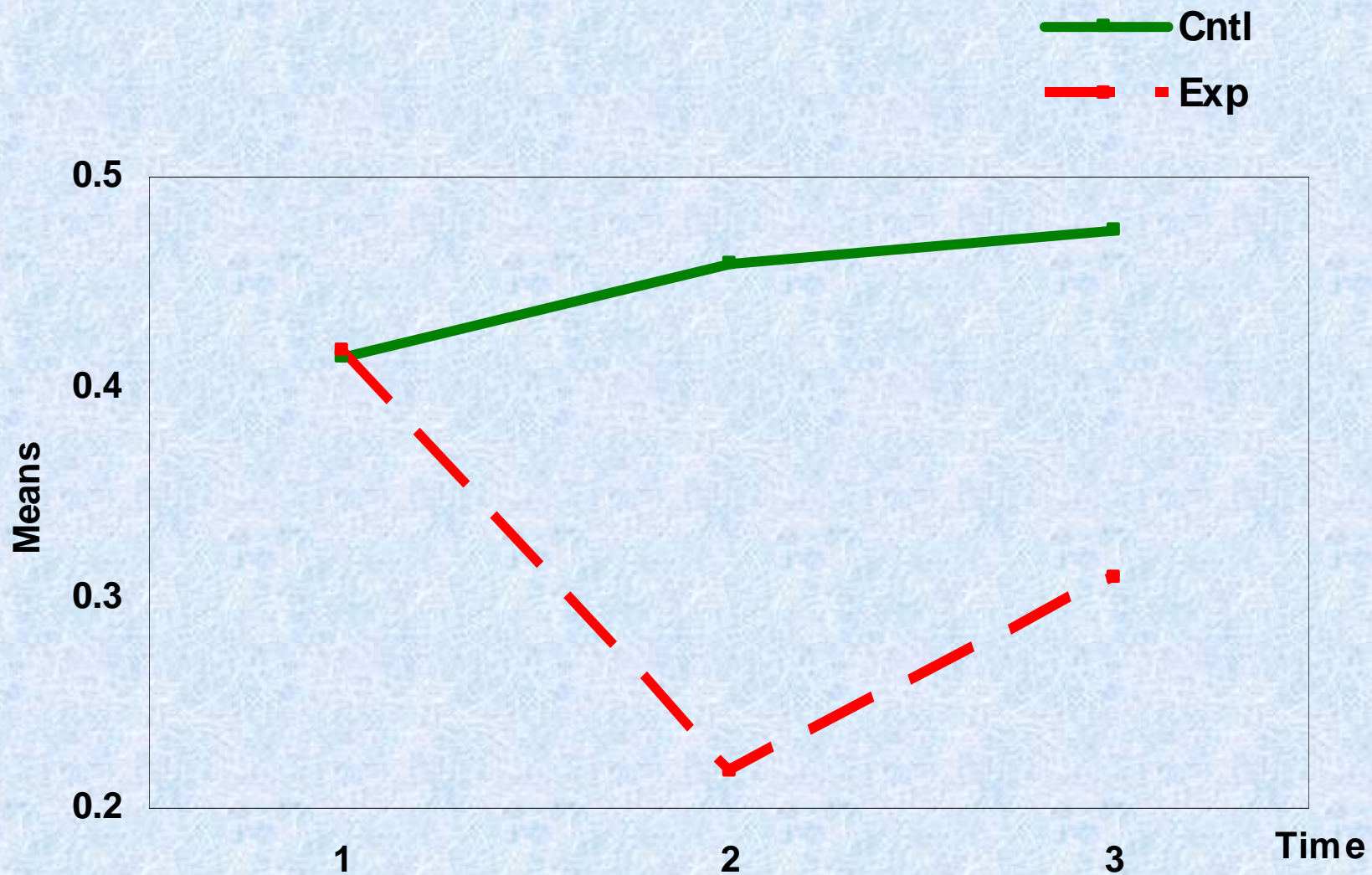
Results of Delivering Intervention

Coping: Self-State:Control vs Experimental



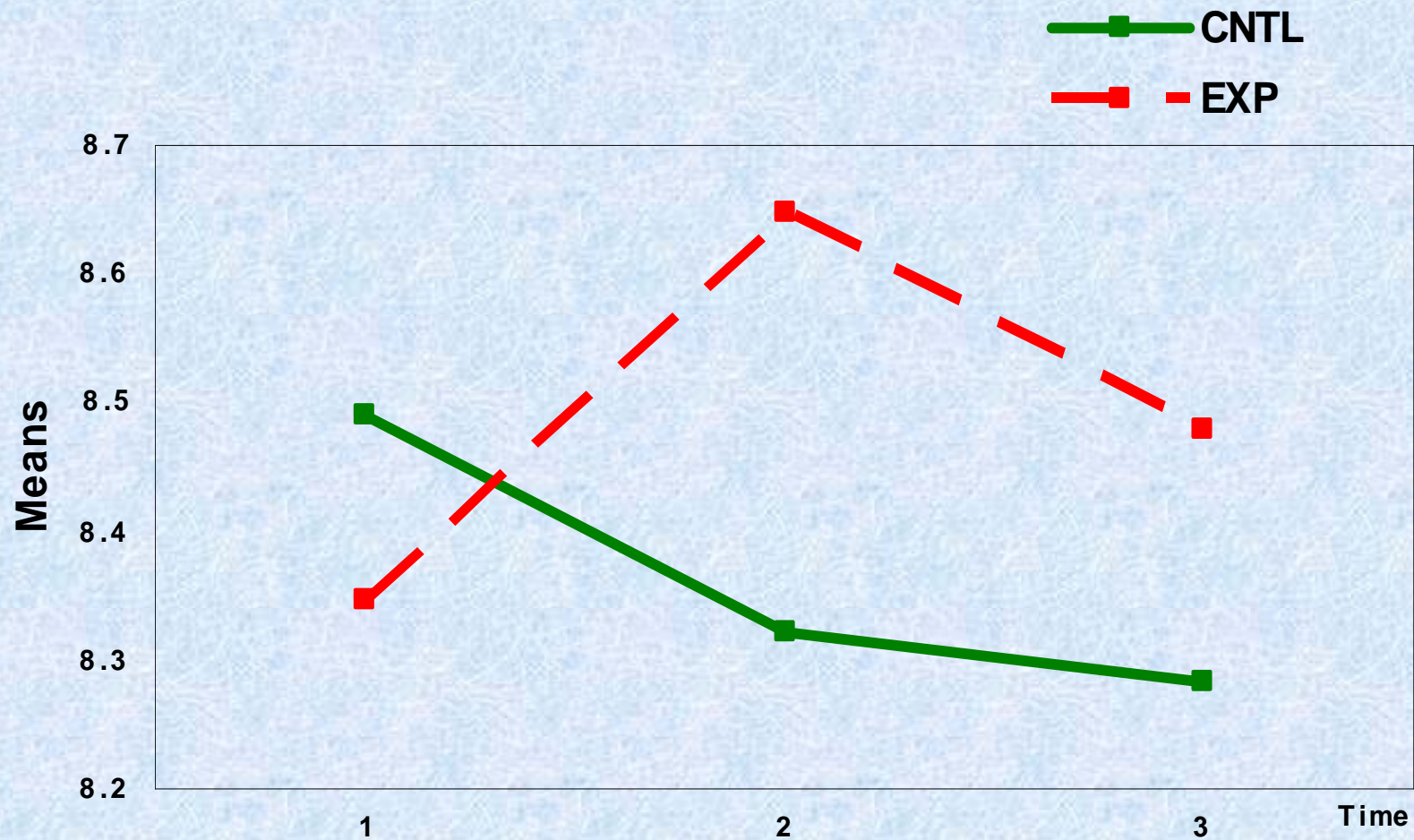
$F=9.46, p<.002$

Coping: Catastrophizing for African-American



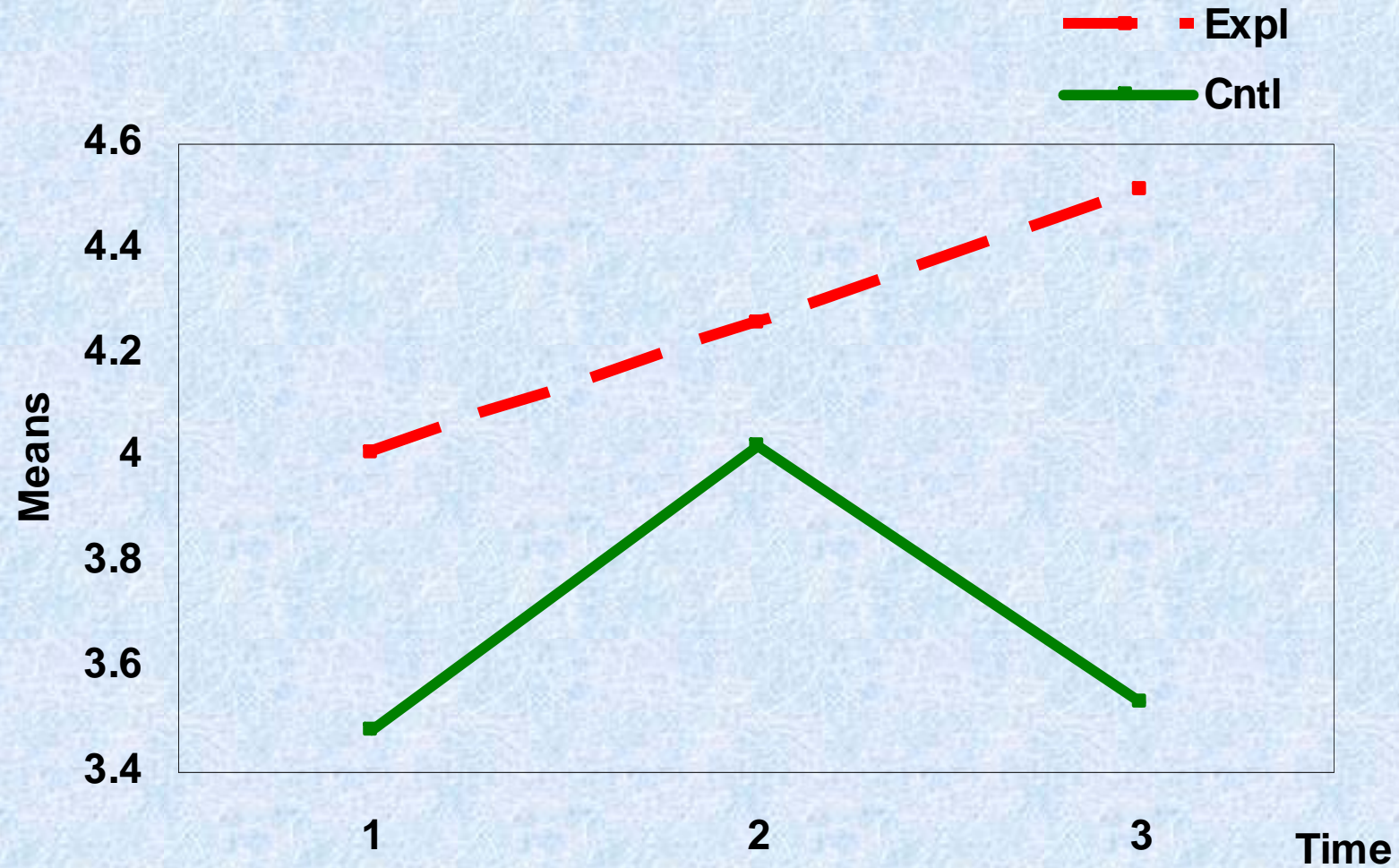
$F=4.49, p<.03$

Cognitive Reframing for African-American



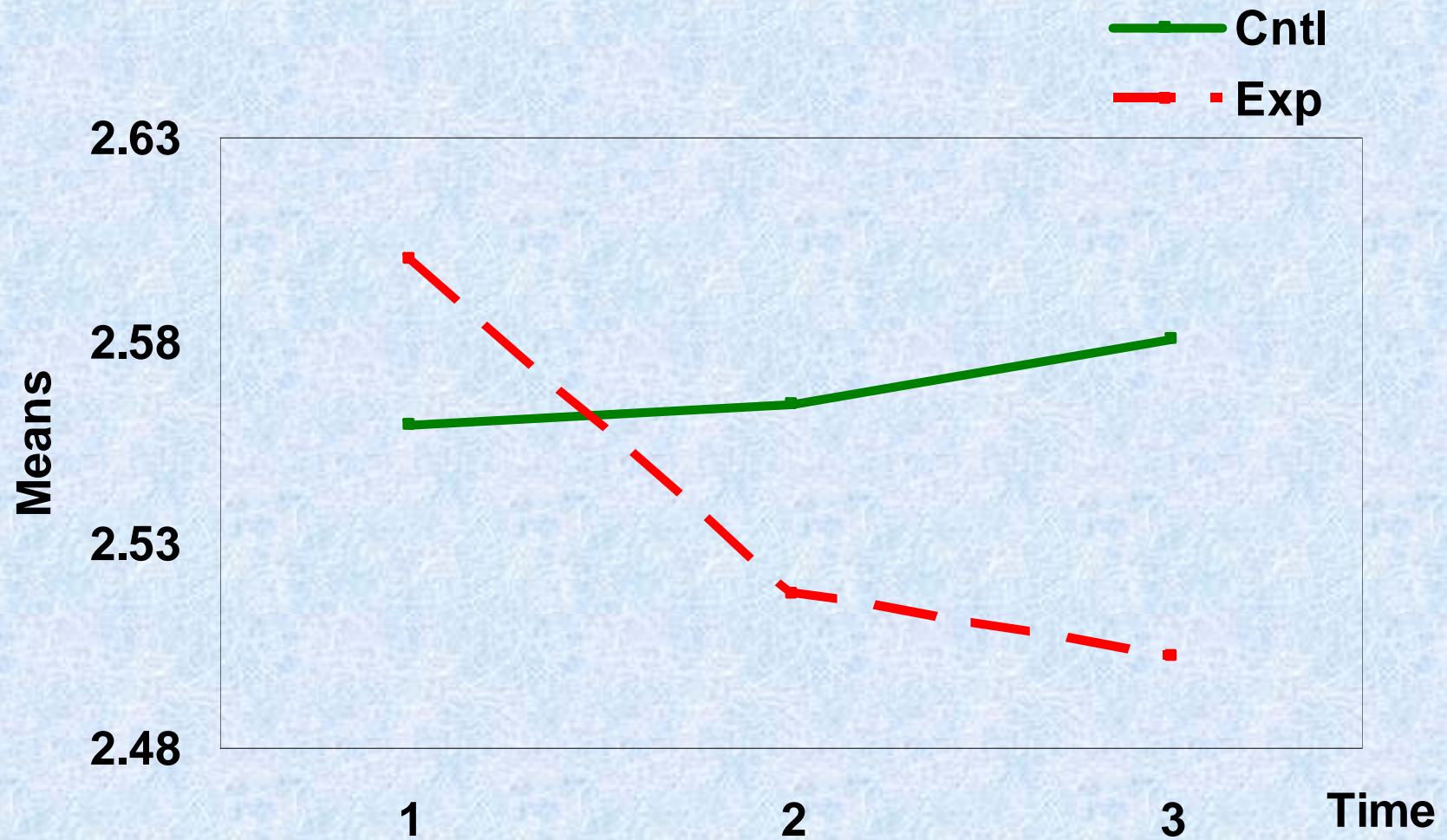
$F=4.84, p<.03$

Coping: Diversion for African-American



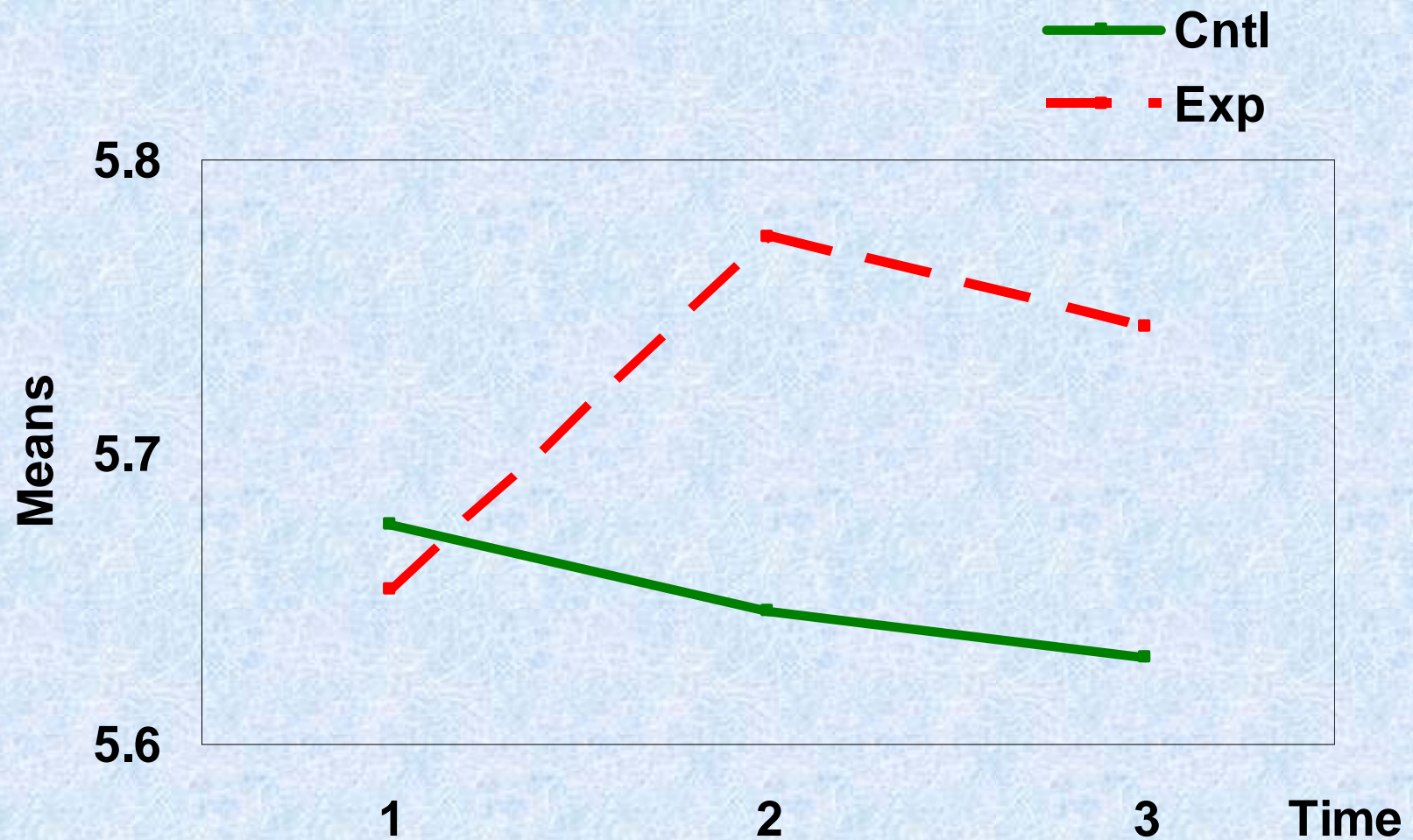
$F=7.54, p<.006$

Uncertainty for Caucasian



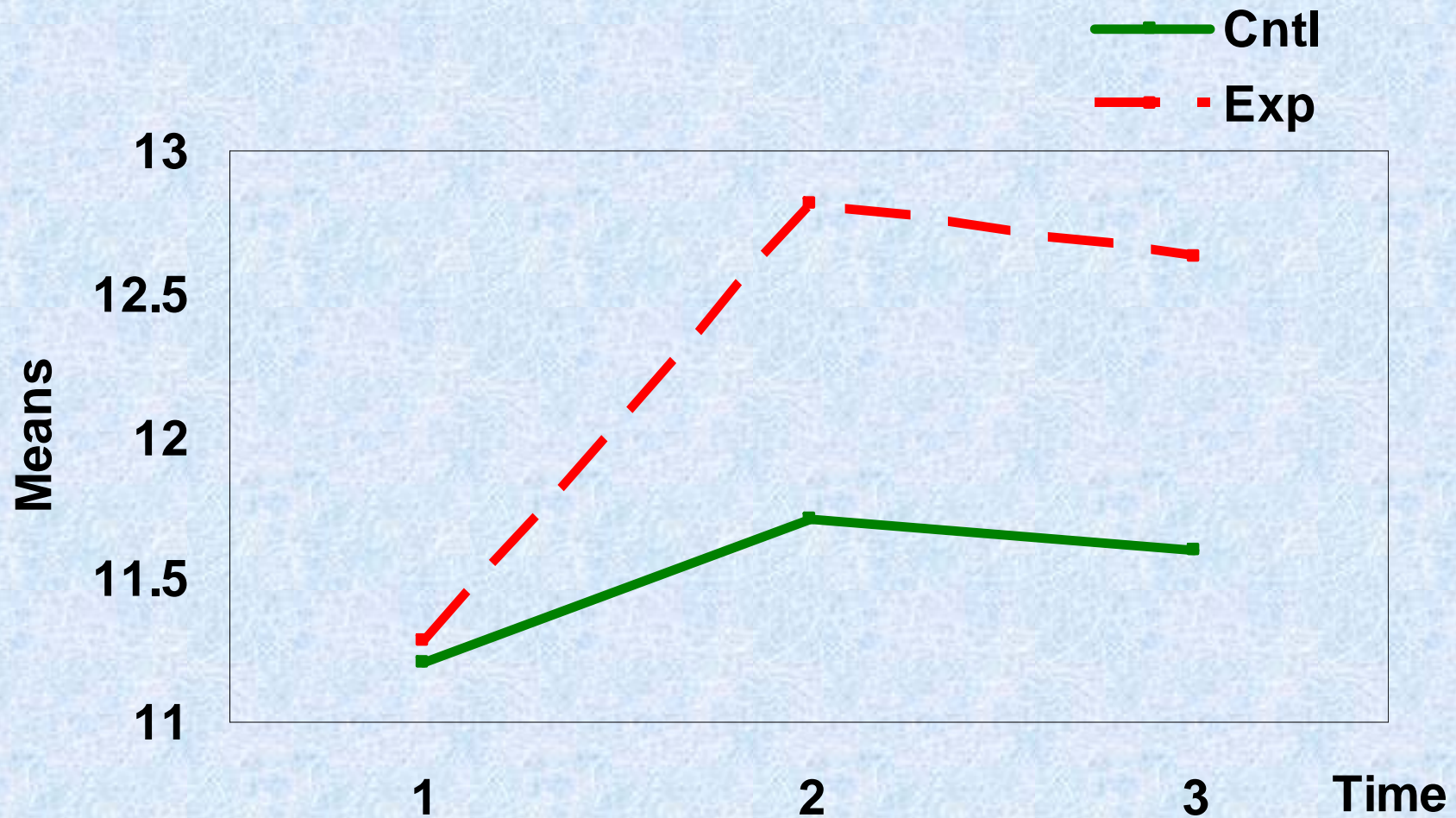
$F=6.32, p<.01$

Coping: Social Support Satisfaction for Caucasian



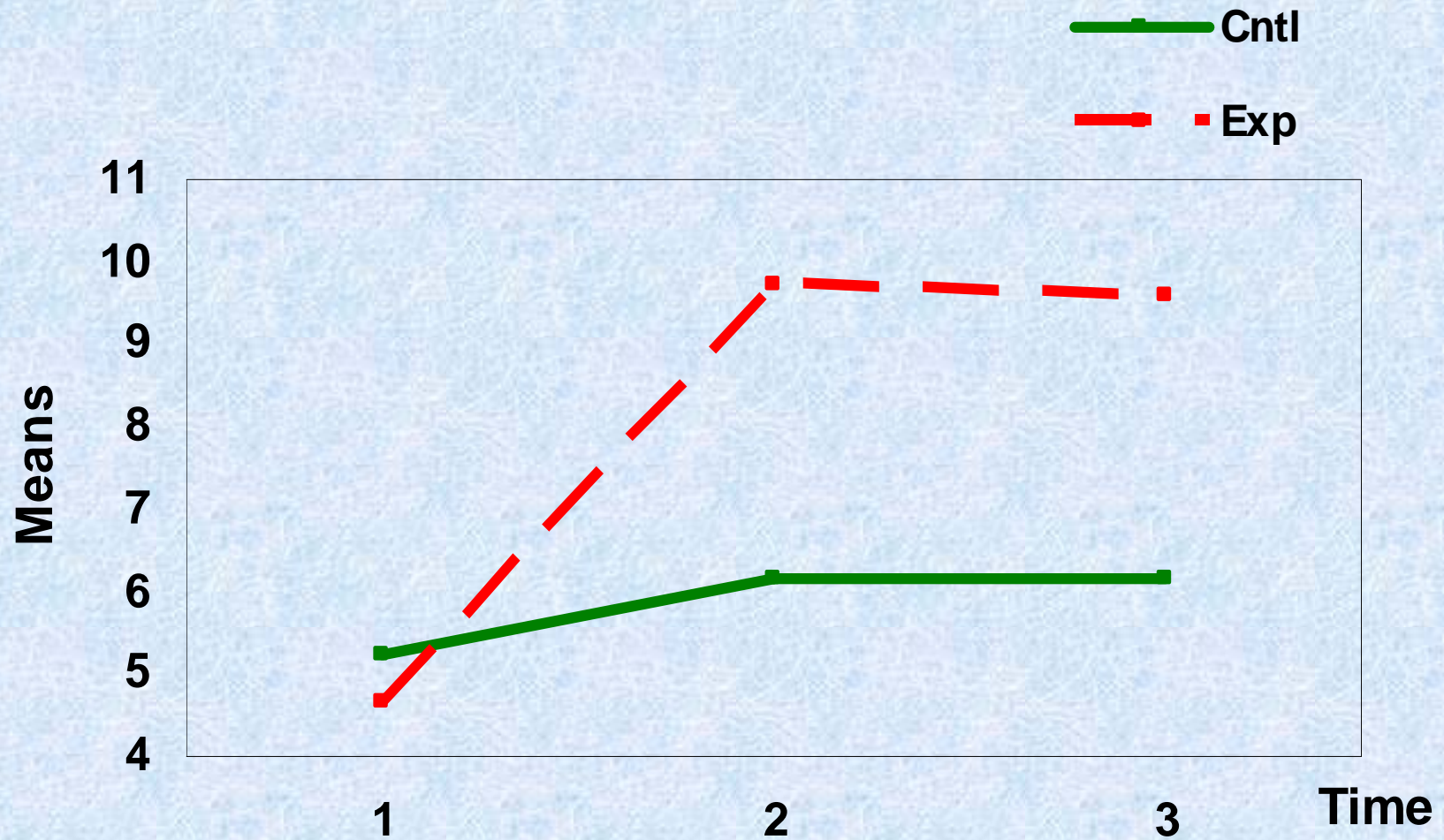
$F=4.37, p<.04$

Cancer Knowledge: Control vs Experimental



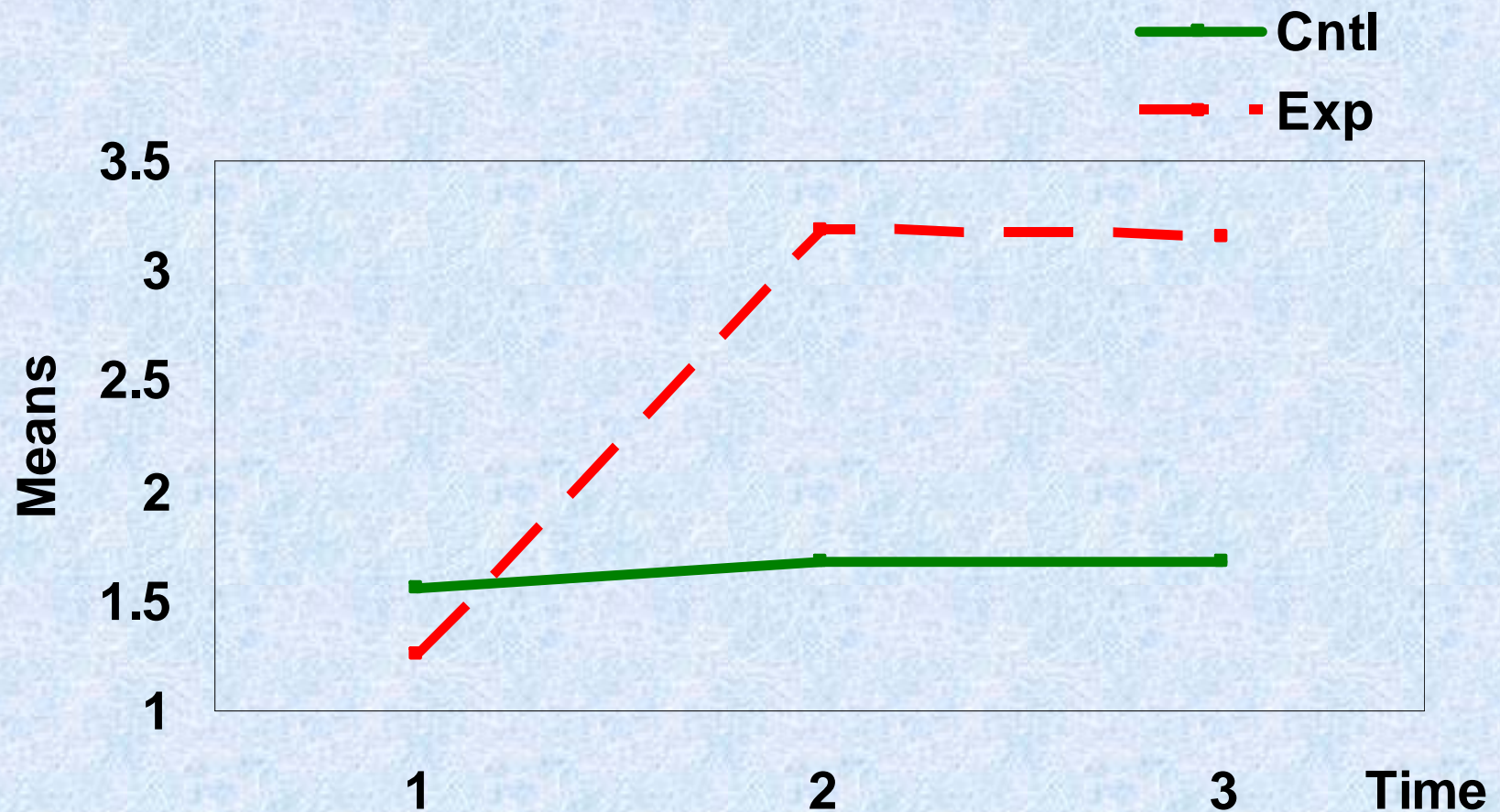
$F=17.85, p<.0001$

Sympton Information : Control vs Experimental



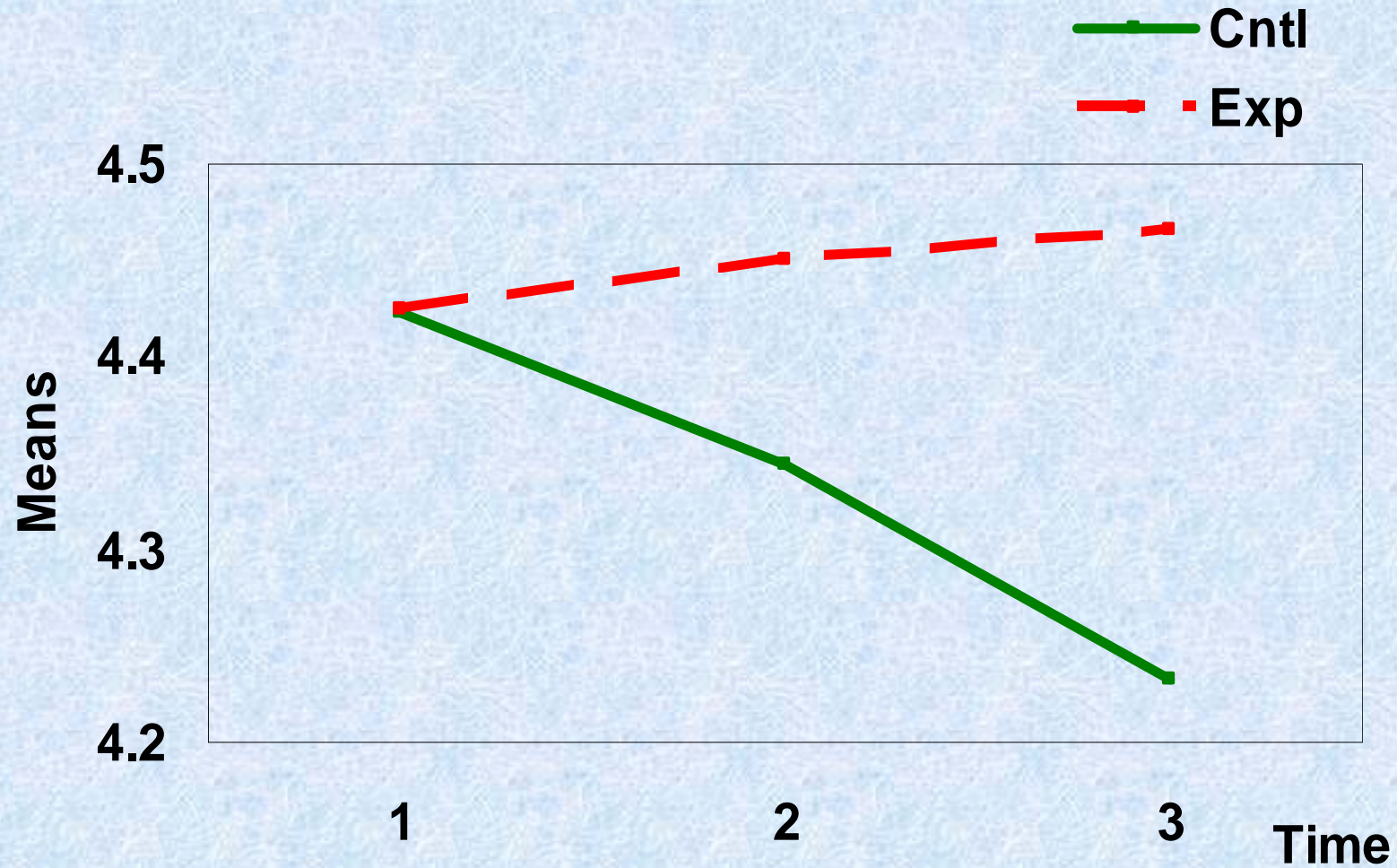
$F=85.60$, $P<0.0001$

Lymphedema Information : Control vs Experimental



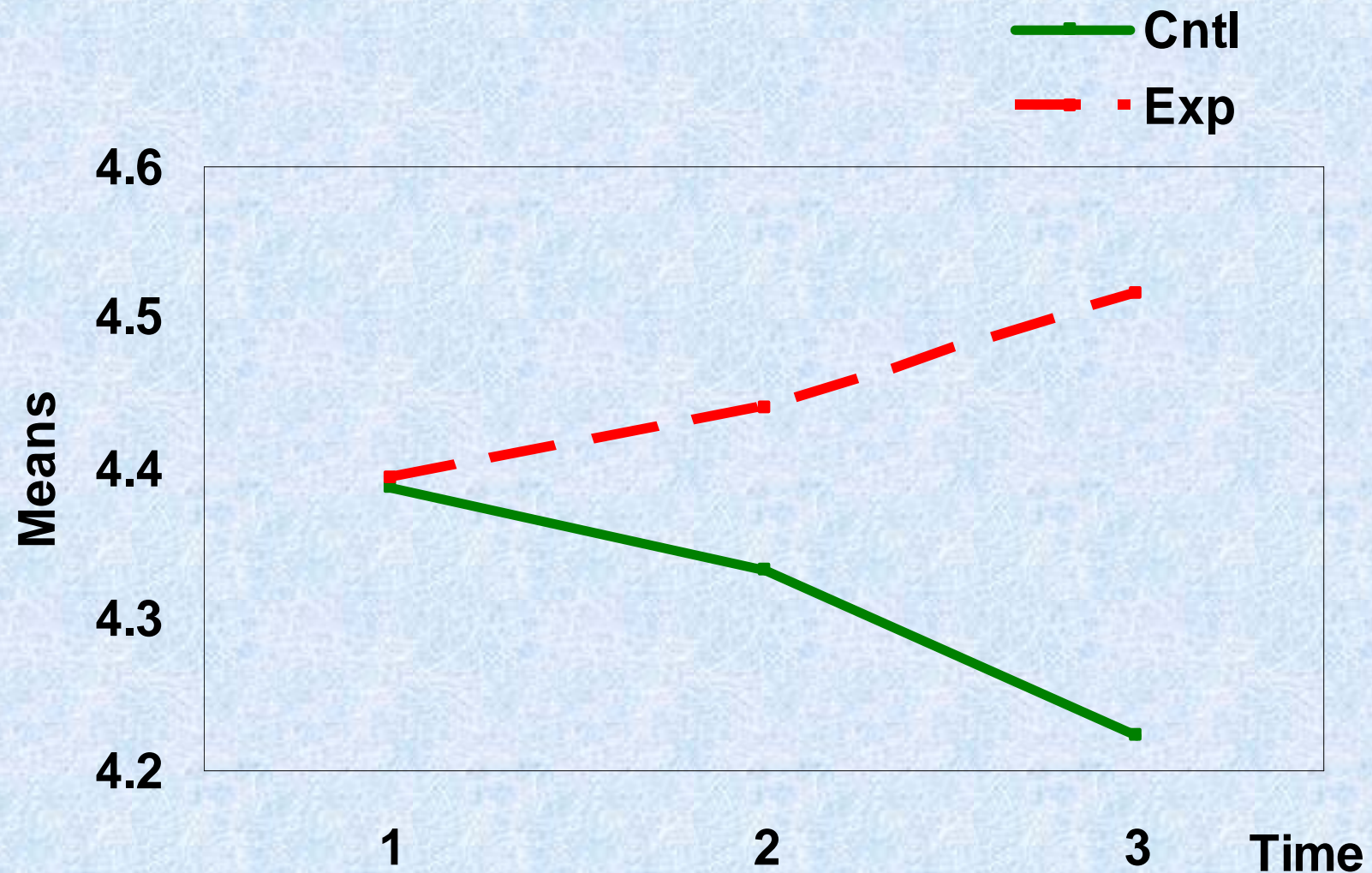
$F=137.65, p<.0001$

Growth Through Uncertainty for African American



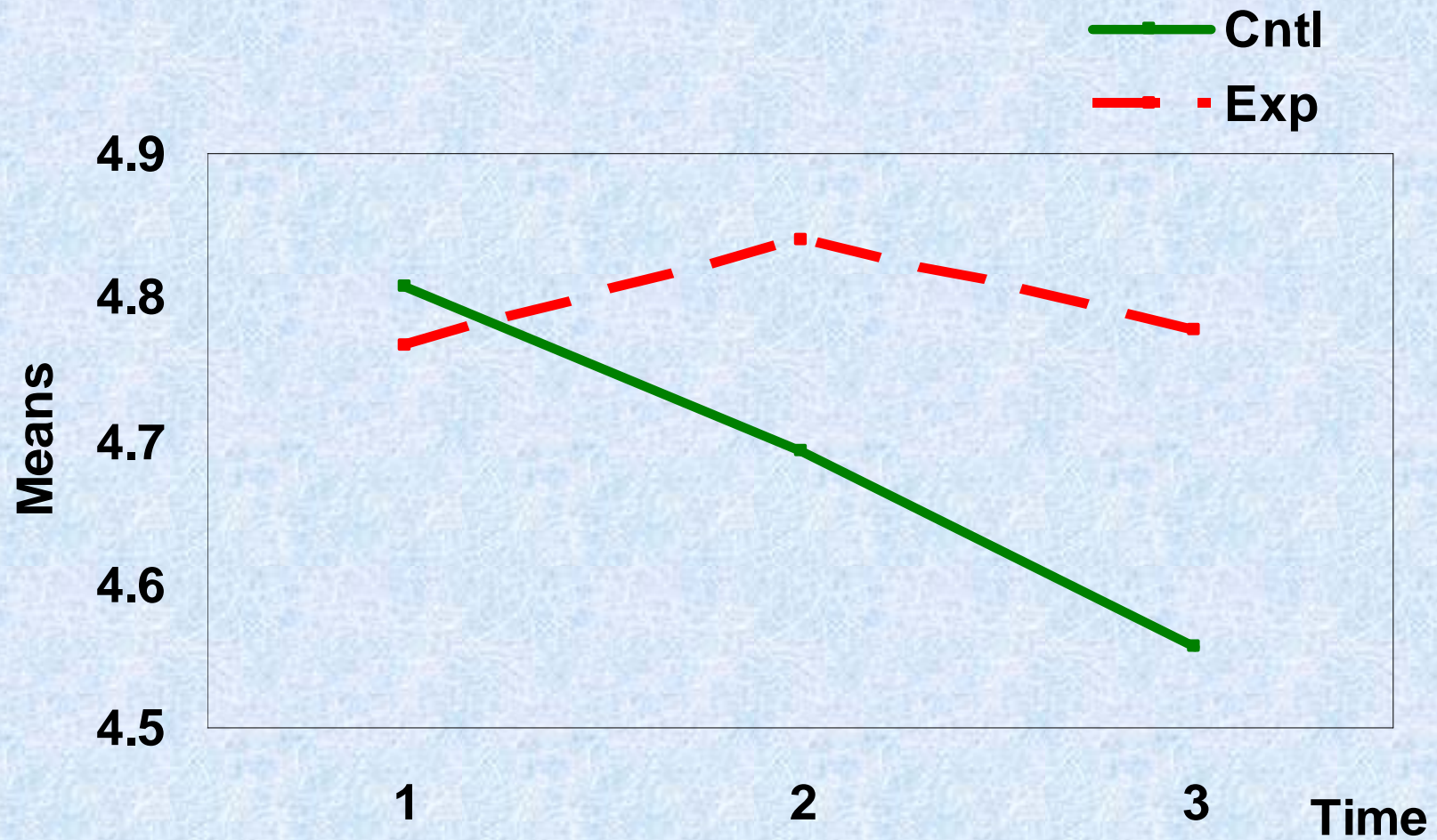
$F=6.53, p<.01$

Growth through Uncertainty Subscale: Greater Flexibility for African American

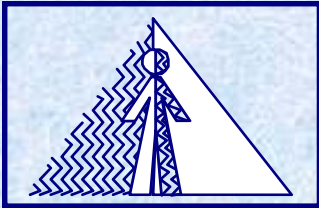


$F=7.11, p<.01$

Growth Through Uncertainty Subscale: New View of Life for African American



$F=5.01, p<.03$



Funding

***Self-help in Breast Cancer and Survivor Breast Cancer* studies were funded by the National Cancer Institute**

***Managing Uncertainty in Stage B Prostate Cancer* funded by the National Institute of Nursing Research and the National Cancer Institute.**